Establishing a volunteer based Dignity Therapy service

Russell Armstrong (Spiritual Care Worker)
Jen Walsh (Volunteer Coordinator)
Barwon Health Palliative Care

PCA Conference 2 September 2015
Concurrent Session A5 - Allied Health
My colleague in absentia
Dignity Therapy - principles & praxis
Dignity (and the work of Prof. Harvey Chochinov)

- Dignity a critical factor in patient perceptions of quality of life and thus will to live
- If dignity worth living or dying for, then worth researching
  - Evidence based understanding dignity
  - Model for how to enhance & protect dignity at end of life
## Major dignity categories, themes and sub-themes

<table>
<thead>
<tr>
<th>Illness related concerns</th>
<th>Dignity conserving repertoire</th>
<th>Social dignity inventory</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of independence</strong></td>
<td>Dignity conserving perspectives</td>
<td>Privacy boundaries</td>
</tr>
<tr>
<td>• Cognitive acuity</td>
<td>• Continuity of self</td>
<td></td>
</tr>
<tr>
<td>• Functional capacity</td>
<td>• Role preservation</td>
<td>Social support</td>
</tr>
<tr>
<td></td>
<td>• Generativity/legacy</td>
<td></td>
</tr>
<tr>
<td><strong>Symptom distress</strong></td>
<td>• Maintenance of pride</td>
<td>Care tenor</td>
</tr>
<tr>
<td>• Physical distress</td>
<td>• Hopefulness</td>
<td></td>
</tr>
<tr>
<td>• Psychological distress</td>
<td>• Autonomy/control</td>
<td>Burden to others</td>
</tr>
<tr>
<td>• Medical uncertainty</td>
<td>• Acceptance</td>
<td></td>
</tr>
<tr>
<td>• death anxiety</td>
<td>• Resilience/fighting spirit</td>
<td>Aftermath concerns</td>
</tr>
<tr>
<td><strong>Dignity conserving practices</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Living in the moment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Maintaining normalcy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Seeking spiritual comfort</td>
<td></td>
</tr>
</tbody>
</table>
Dignity Therapy themes and Dignity Therapy

- Generativity
- Social Support
- Continuity of Self
- Care Tenor
- Maintenance of Pride
- Aftermath Concerns
- Role Preservation
- Maintaining Hope
Dignity Therapy in a nutshell

• Evidence based
• Semi-structured and individualised
• Serves as a guide to
  – elicit memories
  – offer wisdom and provide comfort to loved ones
• Allows participating patients to
  – recognise legacy they leave
  – identify unfinished matters they may wish to address
• Designed to be brief, esp. for patients with fatigue and low concentration
The Dignity Therapy Process

Interview → Transcribe → Edit → Read back → Format → Present document → Interview
• Tell me a little about your life history; particularly the parts that you either remember most or think are the most important?
• When did you feel most alive?
• Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
• What are the most important roles you have played in life (e.g. family roles, vocational roles, community service roles). Why were they so important to you, and what do you think you accomplished within those roles?
• What are your most important accomplishments, and what do you feel most proud of or take most pride in?
Are there particular things that you feel need to be said to your loved ones, or things that you would want to take the time to say once again?

What are your hopes and dreams for your loved ones?

What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?

Are there words, or perhaps even instructions, you would like to offer your family, to help prepare them for the future?

In creating this permanent record, are there other things that you would like included?
Editing the legacy transcript

- ‘Give back’ to client voice she/he had when healthier
- Ensure accuracy of content
- Enhance readability, flow and chronology
- Protect client and recipients of final legacy paper from hurt
- All while preserving uniqueness of client’s voice
The impact/benefit
“When I was told that you could help me record some reflections on life my heart leapt, because it was something that I’ve always wanted to do, but I thought that I’d run out of time because I no longer had the strength and energy to do it myself. I was just delighted with the result, which was beyond my wildest dreams, and sharing it with my family the other day was very special.”

-Trish
“It is a real blessing and source of comfort to me, as Tricia’s husband, to have in print, in her own words, her life’s journey and future desires for me and our three children. Often I have reached for it, looked at the photos, read it and drawn comfort, strength and emotional release through her heartfelt answers on these pages, holding her thoughts close to my heart.”
“I am so thankful for this resource, and for the time and effort put in by the palliative care team. After losing mum I have often found myself turning to this book for comfort; I can almost hear her voice speaking the words to me. It has definitely helped in the grieving process. I also know that in the future I will use it to help others understand who Mum was and the amazing life she led.”
The problem - sustainability
The sustainability issue
The volunteer solution
‘Take off’ in Geelong –
The Geelong Advertiser 21 June 2014

The final chapter

“God, I think it’s so unfair. I get the most beautiful little girl and then I’m not going to be able to be around her. I know I’ll watch over her, and I will. I won’t let her out of my sight.”

In the weeks leading up to the end of her daughter’s life, Terri O’Sullivan has been devoted to ensuring that her daughter Mia is as comfortable as possible. Mia, who was diagnosed with a rare form of cancer when she was just two years old, passed away recently in the arms of her mother.

Terri O’Sullivan’s story is one of resilience and love, and it is a testament to the strength of the human spirit. Despite the challenges she faced, Terri never lost sight of the love she had for her daughter, and she dedicated herself to making sure that Mia’s final days were as comfortable as possible.

In this touching story, Terri shares her journey with Mia, from the day she was diagnosed with cancer to the moment she passed away. She speaks about the challenges she faced, the support she received, and the love she had for her daughter.

Terri’s story is one that will inspire and move anyone who reads it. It is a reminder of the importance of love, resilience, and the power of family. It is a testament to the strength of the human spirit, and it is a reminder that even in the face of great adversity, love can prevail.

The final chapter of Mia’s life is one that will be remembered for years to come. It is a story of love, resilience, and the power of family. And it is a reminder that even in the face of great adversity, love can prevail.
Setting up the Volunteer Program

- Recruitment & Interviewing
- Training
- Ongoing Support
- Development
- Recognition
Recruitment & Interviewing
The Recruitment Process

*Skills based recruitment

Graphic design skills

Office/ Admin skills

Professional background
people skills critical
editing skills

Present document

Format

Transcribe

Edit

Read back

Interview

Edit
Our Recruited Team

• Professional background
  – Journalists
  – Teachers
  – Social worker
  – Former religious leader
  – Family support worker (and carer for dying partner)

• Office/Administration background
  – Medical transcriptionist

• Graphic Design background
  – Graphic Designer
Presenting – our team! (at least part thereof)
Training
The Training Process

- Classroom training:
  - ½ day: Barwon Health volunteer orientation
  - 1 day: palliative care training
  - 2½ days: Dignity Therapy training

- Experiential training:
  - 1-2 interview as observer/assistant
  - 1-2 interviews as lead therapist (with support)

- On-going training & support:
  - 2 hours support/supervision/education each month
Ongoing Support
Ongoing Support

• Informal Support
  – Regular phone calls/ emails
  – Open door policy

• Formal Support
  – Formal briefing and debriefing
  – Monthly support sessions, whole team
  – Notification of death of patient

• Peer Support
  – Volunteer-to-volunteer support and mentoring
Development
• Volunteers have a “volunteer career”

• Volunteers seek development opportunities

• We created 3 volunteer roles within Dignity Therapy:
  – Trainee
  – Volunteer
  – Mentor
Volunteer Roles

- Trainee
- Volunteer
- Mentor

Support Required ➔ Volunteer Autonomy
Recognition
Recognition

- **Informal Recognition**
  - Regular encouragement and recognition of good work
  - Volunteers profiled in newsletter
- **Formal Recognition**
  - Including in National Volunteer Week events
  - Mentor Volunteers offered attendance to PCA pre-conference session
  - Thank you cards
The program in practice
First year of full volunteer program

• Guidance documents developed and reviewed

• Increased ability to offer Dignity Therapy to patients (already doubled first year with staff only, and still growing)

• High retention of volunteers
The outcome (over 3 twelve month periods)

- Volunteer led DT with staff supervision
- Volunteer led DT with staff assisting
- Staff led DT with volunteer assisting
- Staff only DT

Years:
- 2012-2013
- 2013-2014
- 2014-2015
- Next year?
The Unexpected - CHALLENGES

• Getting it Right!
  – Offering DT at the right time
  – Offering DT to the right patient
  – Matching the patient with the right volunteer

• Droughts & Floods of referrals

• Managing volunteer expectations
  – Workload for volunteers
  – Changing patient status
  – Fluid patient appointment times
The Unexpected - BENEFITS

• Flexible Scheduling
  – After hours
  – Weekends
  – Multiple visits

• Quality improvement in response to volunteer feedback
  – Working in pairs
  – Introducing DT
  – The read back

• Dignity Therapy “+”
  – Companionship & Respite Support
  – Bereavement Support
Closing reflections
Volunteer perspective

Working with the Dignity Therapy Program at Barwon Health is an absolute privilege. To be allowed into the inner sanctum of a dying person's thoughts and last wishes, and knowing that you are helping them communicate a lasting legacy to their loved ones is so incredibly intimate and special.

I have consummate respect for the sanctity of my role and feel honoured to be a part of this incredibly worthwhile Program.

Lee, volunteer typist, pictured with client Jenny
The reward!

Photo courtesy of Nigel Hallett
Final words

“We pick up this book now and we read it, and we can hear Shannon speaking. That’s such a comfort because we still have part of Shannon here. That has helped us no end, it really has. What you have given us we will cherish forever. It’s a gift more precious than gold.”

Dignity Therapy participant Shannon with her daughter; Shannon participated in DT a fortnight before her death.
Questions

• Dignity in Care website